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TO: Members of the Legal Process Subdivision of AAMD  
FROM: Stan Herr, Chairperson

As never before, the members of this subdivision need to take a leadership role in defending the rights of mentally retarded persons. In recent weeks, you have received mailings from President Carl Haywood stressing the need for legislative advocacy with members of Congress. I would only reaffirm the urgency of such continuing action, if we are, among other goals, to

1. Preserve hard-won statutory principles of non-discrimination and related entitlements to services, such as special education and least restrictive care, entitlements which must survive even these periods of budgetary constriction;
2. Defend the Legal Services Corporation, the Protection and Advocacy Systems, and other public advocacy programs against abolition or crippling cuts. These and like resources are critical to amplifying the voices of mentally retarded persons and helping these individuals to safeguard their rights.

Rud Turnbull, one of our members who previously served as chairperson of this subdivision, has written a concise and compelling paper on the hazards of block grants and a waning federal role, entitled "The Crisis in Mental Retardation." With his permission, I am sharing a copy with you. As he quite correctly explains, the "current debate about the budget, is not the crisis, only symptomatic of it."

The recent decision of the United States Supreme Court in *Pennhurst State School & Hospital v. Halderman*, (no. 79-1404, April 20, 1981) is another "reminder that even preserving existing statutory rights is not necessarily enough. While this legally narrow opinion only dealt with the Developmental Disabilities Act, it seems to invite Congress to reaffirm, with even greater precision, its intention to confer the statutory right to treatment and habilitation in the least restrictive environment.. It is also Important to be clear as to the many issues the Supreme Court did not. decide; including the federal constitutional, Section 504, and state statutory ground for supporting the legally enforceable right to such habilitation.

By now, it should be apparent that the Annual Meeting

in Detroit (May 25-29, 1981) occurs at a critical juncture. Its theme, "A Decade of Change: From Rights to Realities," reflects the legal process subdivision's concerns and lead. In addition to the plenary session organized by our subdivision on the "Legal Rights of Persons with Mental Retardation," other outstanding presenters will be exploring such topics as the meaning of the Pennhurst case, recent Congressional and Federal Executive developments, the lawyer's role for retarded clients, problems of investigating abuse neglect, new directions in litigation, the mentally retarded offender, confidentiality problems of informed consent, the advocacy process in special education, and the roles of social workers in court proceedings. Members of the Legal Process Subdivision are also invited to gather for an informal luncheon and meeting on May 27th. In short, there is much information to exchange, many coalitions to strengthen, and personal and professional relationships to renew. I look forward to meeting many of you in Detroit,

May I add an author's query: AAMD several years ago published an official position paper encouraging the development of human rights committees. I would welcome any comments or your views of the roles and limitations of such committees, and whether any updating of the AAMD position on this subject is necessary or desirable.

Americans have been leaders in the world-wide struggle for the rights of disabled persons. It seems especially ironic that in 1981, the International Year of Disabled Persons, our Government must be restrained from its Great Leap Backward. Please *do* whatever you can to raise your voice, and to urge your friends to speak out in order to keep this country from sacrificing the rights and interests of *its* most vulnerable citizens.

# "The Crisis in Mental Retardation"

By

H. Rutherford Turnbull, III Chairman,  
Department of Special Education The  
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at

Young Adult Institute, Conference on Handicapped People New  
York N.Y., April 10, 1981

"Ideas are inherently dangerous because they deny human facts."  
John Fowles, The Ebony Tower.

A crisis of major proportions looms before mentally handicapped people in the wake of the November, 1980, elections. The current debate about the federal budget is not the crisis, only symptomatic of it. The true crisis is not even the future relationship of the federal government to mentally handicapped citizens. It is--one would have thought the issue is beyond cavil--whether mentally retarded citizens are expendable, whether the benefits of this rich country should go only to the most meritorious, where merit equates with intelligence. The relationship is the pivot for the real debate and, as such, worthy of our careful scrutiny. Indeed there is no more propitious time than now to examine that relationship and its prospects. To fail to do so would be to concede that the relationship is ill conceived; it would be to acquiesce to the present Administration's vindictive injustice, its attempt to redefine it. I will analyze the relationship and argue that it must be maintained in the face of the immediate frontal attack upon it. To permit an atrocious distortion of that relationship, such as is now proposed, would be to jettison retarded citizens from the community of humane people.

The federal-citizen relationship is a direct one. That this is so is evidenced by four types of federal laws, defining the relationship. First, the federal government grants handicapped people rights to substantive benefits, such as the right to an appropriate education (Education for All Handicapped Children Act) or the right to protection and services in institutions (Developmentally Disabled Assistance and Bill of Rights Act). Second, Congress enacts rights to be free from discrimination; Section 504 of the Rehabilitation Act (1973 Amendments) typifies this right. Third, it entitles handicapped citizens to certain benefits, as through several titles of the Social Security Act. Finally, Congress passes enforcement legislation, designed to enable handicapped citizens enforce their rights under other law; good examples are the procedural safeguards of the Education for All Handicapped Children Act and the right-to-sue provisions of Section 504.

There is a compelling reason for the direct federal-citizen relationship, a justification for the relationship embodied in these types of laws. Quite simply, it is that a handicap is a distinction that makes a difference in a person's life; it is a characteristic that not only justifies but also requires a special relationship of the federal government to handicapped citizens. All too often, the handicapped citizen has been denied an opportunity for education, employment, community

residence, and other opportunities that nonhandicapped people take for granted. And the denial has been occasioned solely by reason of the fact that the person is handicapped. State and local governments either have not served these citizens at all or have served them only inadequately and, in important ways, unconstitutionally. To protect handicapped citizens against discrimination in these important areas of life, to give them opportunities for independence, it has been necessary for the federal government to enter into a direct relationship with them. Were it not for their handicaps and the ways it has burdened them in state-local governments' activities, they would not be able to lay such a compelling claim to the direct relationship. Because of their handicaps and a bitter state-local history, the relationship must be continued.

The present relationship of the federal government to handicapped people takes five different forms. First, in order to help them cope with the extraordinary demands of handicaps, the federal government provides direct assistance to handicapped people and their families as, for example, by the provisions of the Social Security Act granting financial aid to disabled people, social services for needy handicapped citizens, and medical-care assistance to income-eligible disabled people. Second, to discover ways of ameliorating or preventing handicaps, it performs a leadership role in research, model program demonstration, and training in areas of vital importance to handicapped people; the National Institute of Health and the National Institute of Habilitation Research are but two examples of this role. Third, the federal government induces and assists states in adopting and maintaining such essential cost-effective and humane state-local services as education, vocational training, and institutional and community housing. Next, the federal government assures handicapped people that they will have rights to services; the Education for All Handicapped Children Act and the Developmentally Disabled Assistance and Bill of Rights Act illustrate this role. Finally, it assures handicapped people that they will have the means to acquire and enjoy their rights; to this end, Congress has established and funded the Legal Services Corporation and, under the DD Assistance and Bill of Rights Act, the "protection and advocacy" systems and state planning councils for developmentally disabled citizens.

Should the unique direct relationship between the federal government and its mentally disabled citizens will be allowed to continue? In its omnivorous appetite for simplicity, its constitutional intolerance for complexity, the present Administration proposes to change the relationship dramatically. In essence, it would substitute "block grants" for "categorical grants" to state and local governments in the following areas: education, social services, health, preventive health, and energy and emergency assistance. To put it another way, federal programs that directly and indirectly benefit mentally disabled citizens would be consolidated with each other and with programs for other citizens, and federal financial assistance, presently required to be spent for retarded people, would be spent on them only in the unlimited discretion of state and local governments.

The Administration favors block grants because they purportedly will

- 1) reduce the costs of administering federal, state, and local programs;
- 2) reduce the burdens of regulation; and 3) increase the flexibility available to state and local governments in serving, or not

serving, retarded and other handicapped citizens. There is, however, another way of looking at block grants, particularly if one's major concern is with the life-time status of retarded citizens. A careful analysis of these platitudes will show them to be as barren for retarded citizens as a desert.

A hallmark of block grants is the unfettered discretion they give to state and local governments to spend none, some, or all of the federal money on retarded and other handicapped citizens. Given that retarded citizens are a minority of relatively powerless handicapped people, they have no assurances that they would receive the benefit of any federal funds. This prospect is made more real because, under the education and social services block grants, their present rights to service (e.g., under Education for All Handicapped Children Act and Developmental Disabilities Bill of Rights Act) would be repealed. Without rights to service, they will have no leverage to require any federally financed services.

(1) It is not justifiable to approach administrative costs-savings by imposing unacceptable consequences on retarded citizens. Nor is it clear that administrative costs would be substantially reduced by block grants. Block grants will not assure increased state and local government efficiency; indeed many administrative costs are incurred solely because of state and local regulations, not federal ones. Federally financed programs still will have to be administered; the planning and coordinating functions of state DD planning councils still will be required. Unlike present federal categorical-grant laws, block grants will not impose a ceiling on administrative costs; there will be no assurances that more money will be spent for direct-service purposes. And, even if one assumes a 10% administrative cost saving, the reduction of federal aid by 25%, coupled with an inflation rate of nearly 10%, will result in 25% less money for direct services.

(2) Under the pretense of "reducing regulatory burdens," block grants actually repeal retarded citizens' federally assured rights to federally financed services. For example, the education block grant will repeal the Education for All Handicapped Children Act, P.L. 94-142; the social services block grant will repeal the Developmental Disabilities Bill of Rights, the protection and advocacy systems, the Legal Services Corporation, and the ICF-MR program. These rights and their implementing regulations are necessary because they enable retarded citizens and their representatives to cure the default of state and local governments to serve them at all or serve them adequately; they implement retarded citizens' federal constitutional rights; and they set professionally sound standards for state and local governments.

(3) The claim that block grants will grant state and local governments increased flexibility undoubtedly is true. But with such expansive flexibility, state and local governments can choose not to serve retarded people at all or at diminished levels; they can substitute federal money for state and local money, thereby reducing the overall level of services for retarded citizens; and they can shift the taxing responsibility to local governments. To do this is to incur the likelihood of a Proposition 13 response; this in turn would be to

the detriment of retarded and all other dependent citizens, including many nonhandicapped ones, and to the likely detriment of members of Congress who endorse—and will come to rue—the shift of responsibility. The voters cannot be so easily fooled.

More dramatic, however, would be the irresponsible overall effect of block grants, as presently proposed, on mentally retarded citizens. Unless the block grant concept is abandoned or substantially modified, it will cause intolerable adversities for these citizens and their families. In fact, block grant proposals are nothing less than a frontal assault on the network of services that constitutes the only guarantee that retarded citizens will not be consigned to lives of unwarranted and unnecessary indignity, frustration, nonproductivity, and dependency.

Preventive services—prenatal care, maternal and child health, elimination of lead-based paint causes of retardation, and genetic disease counselling—will be consolidated into a health block grant.

The education block grants will, among other things, consolidate early childhood programs; repeal the Education for All Handicapped Children Act (P.L. 94-142); repeal the federal education assistance to institutionalized children (P.L. 89-313); target education money only for severely handicapped children; and fold in teacher training programs of national significance. These grants will jeopardize and, in some instances, completely abolish the basic right of retarded children to an appropriate public education.

The social services block grant will repeal the Developmentally Disabled Assistance and Bill of Rights Act, the Rehabilitation Act, and Title XX of the Social Security Act; it also will consolidate and make discretionary such important programs as DD, child abuse, foster care and adoption, and social and child welfare services and training. Its impact will be catastrophic. Retarded people will lose their categorical eligibility for certain essential, cost-effective programs (such as vocational rehabilitation); they will have to compete—and probably unsuccessfully—for money that can all be spent for traditional day care, foster care, and other services to the poor; they can expect no improvement of any services they might receive because there will be no federal focus on them alone; they may be deprived of such mandatory services as protection and advocacy systems, which will become optional; they will lose assurances to such essential programs as vocational rehabilitation, supplemental security income, social security disability payments, and representation by the Legal Services Corporation because all of these programs are marked for elimination; they may be deprived of the benefit of planned services because the State Developmental Disabilities Councils may be discontinued; they can expect that they will lose the protection of the anti-discrimination regulations implementing Section 504 of the Rehabilitation Act because the act is targeted for repeal; and they can expect such newly authorized services as the subsidy for hard-to-place children will never be launched.

By repealing rights-granting laws (e.g., Education for All Handicapped Children Act and Developmental Disabilities Assistance and Bill of Rights Act); by making ICF-MR programs optional; and by withdrawing

mandates for protection and advocacy systems and authority for the Legal Services Corporation, block grants make it unlikely that retarded citizens will have any way to enforce their constitutional rights. For them, that sturdy oak, the Constitution, would be whittled into a toothpick.

By making education and vocational training optional, block grants remove any assurances of cost-effective training. They make it possible--perhaps likely--that retarded citizens will be made more dependent and more costly to care for.

By making the ICF-MR program optional, they make it possible for states to avoid the life-safety and staff-resident ratio standards that make for humane and constitutionally acceptable institutions and community-based facilities. They also make it probable that states, facing the demands to keep their large institutions, will deliver federal money into them, to the exclusion of community-based programs; in short, they may put the brakes on institutional reform and deinstitutionalization.

By putting personnel preparation and training money in the jurisdiction of state educational and social service agencies, themselves consumers of higher education, they make it difficult to expect that nationally significant innovations in training and demonstration models will occur.

By subjecting preventive services to competition with direct services for reduced federal money, they insure lower funding of prevention and, in the long run, higher costs of care.

And by allowing states to abandon foster care, adoption, and child abuse programs, they directly and immediately jeopardize the well being of retarded children and their families.

Like most excesses of vogues, they overreach themselves; they are anodynes whose potential to harm surpasses the likelihood they will temporarily ease our pain. These "consolidation programs" wholly vitiate the direct relationship of the federal government to mentally disabled people. They entirely disregard the fact that a mental handicap is a distinction that makes a difference, that justifies a special relationship between the federal government and retarded people. They blindly ignore two important facts of history: many states never performed these services or performed them inadequately. At the insistence of fanatical ideologues, they overgenerously and incorrectly interpret the 1980 election results—there was no mandate to repeal the special relationship to special citizens. With unblemished chicanery, they attempt to sell a cruel hoax to states, local governments, and the electorate—that fewer services will indeed satisfy the interests of the citizenry.

In short, the health, education, and social services block grants are apocalyptic for retarded citizens. If enacted, they would reverse years of progress. They herald a return to purgatory, a revisiting of bedlam, a renaissance of shameful dark ages in the lives of retarded citizens.